

MODELS OF EFFECTIVE ADVOCACY FOR CHILDREN*

EDYTHER FIRST

Chair, Health Section
Citizens' Committee for Children
New York, New York

CHILDREN cannot organize and speak out for themselves, so advocacy organizations must exist to defend their interests. And since children's well being does not depend on laws and budgets alone but at least as much on the way in which programs affecting them are administered, advocacy for children must encompass both.

We know that over time some child advocacy organizations are listened to more often than others by the decision makers, and the obvious question is why. There is no single formula for an effective child advocacy organization, and it would take a much broader survey than we are engaged in today to produce a full set of keys to success. But as Mr. Ensminger and I talk about particular models that have worked, some of the qualities that can make a difference will certainly suggest themselves.

From long association I see the Citizens' Committee for Children as an organization that exerts a steady positive influence on the response to children's needs in New York City, including their health care needs. In my opinion its effectiveness derives in large measure from certain organizational ingredients, and I'd like to touch on each of these in turn.

I would place first among the Committee's special qualities its composition and the role assignments within it. It is an invited body of about 200 members chosen for three-year terms because of their demonstrated concern for the needs of children, especially disadvantaged children, and the knowledge, energy, and skills they can contribute to the organization's work. Its membership includes lawyers, judges, physicians, nurses, social workers, and lay community leaders. The Committee has a small professional staff of very high quality, headed by Executive Director Bernard C. Fisher. The staff develops the Committee's information base and organizes and takes an active part in its advocacy efforts. Obviously the expertise and dexterity of its staff

*Presented as part of the 1988 Annual Health Conference, *Child Health: One Hundred Years of Progress and Today's Challenges*, held by the Committee on Medicine in Society of the New York Academy of Medicine May 18, and 19, 1988.

are crucial to achieving its objectives. But that can also be true of very different advocacy organizations. What is unique in the Committee's model is the contribution made by its membership.

In many advocacy organizations members play a distant and confined role. In the Citizens' Committee for Children the board and many members work side by side with staff in all phases of its substantive activities—planning projects, doing field work, debating the recommendations that should emerge from studies, reviewing draft reports, and sharing the responsibility for presenting the Committee's views in public forums. I see the quality and commitment of its members as one of its greatest strengths. The presence of volunteers in advocacy activities seems to convey to legislators and others the seriousness of public concern about an issue.

Members work in the specialized sections into which the Committee is divided—child welfare, education, health, and so on—or in ad hoc committees, or they may be available as consultants if their schedules preclude meeting attendance. The breadth of the Committee's agenda, the range of expertise available within it, and the cross-pollination that takes place among different disciplines are of inestimable value in arriving at sound and practical positions, since almost every issue seriously affecting children's lives cuts across professional lines.

A second distinguishing characteristic of the Committee as an advocacy organization is its method of work. The key words here are objectivity and knowledge. The Citizen's Committee for children accepts no government contracts, so it is not financially dependent on those whose policies it may seek to change. Similarly, it avoids the provision of direct services so that it will not be biased in favor of a particular service model.

But the most important component of its method of work is the fact that it acts on the basis of knowledge both at a professional level and from observing what is happening at the service level. Before the Committee adopts a course of action, its members and staff have not simply consulted leading experts but have usually gone out to see first hand how well the programs designed to meet a particular problem are operating. Although the Committee publishes many reports, their purpose is not to expand the literature on the subject. We hope that they will inform others, but their recommendations grow out of our monitoring and constitute our agenda for advocacy.

I cannot overstate the importance to the Committee's effectiveness of the fact that its members as well as its staff have seen what they speak about. Remembering the children with HIV infection on a hospital ward, remembering the mothers and restless youngsters sitting for hours in crowded clinic

waiting-rooms, Committee spokesmen are not just mouthing statistics to prove that a problem exists or supporting some abstract proposal for a remedy. They have seen what is needed and they become better and stronger advocates—often impassioned missionaries.

A third identifying mark of the Committee is its advocacy style—the manner in which it attempts to bring about change. Since it is not an ad hoc group formed to achieve a single goal but a long-term advocate that will need continuing input and influence, it rarely operates in a confrontational, antagonistic mode. Rather, it works quietly and persistently to persuade those who can affect change.

Our credo at the Committee is that we shall ultimately achieve results by our command of the facts, our doggedness, and the inexorable logic of our recommendations. Consequently we stay with an issue year after year and seize upon any development that offers hope for a renewed drive if we have not attained our goals. Decision makers cannot hope that we will disappear if they ignore us. They know that we shall continue to present our views and press for our recommendations through every available channel: published reports, face-to-face meetings with officials and providers, letters and telephone calls, testimony at public hearings, contacts with the media, and—where appropriate—joining forces with coalitions that have similar goals on a particular issue.

A cardinal principle of successful advocacy is that we cannot expect instant victory and stalk off the field if we do not get it. We accept as a given that it will usually take years of unrelenting pressure to achieve a change the desirability of which we find self evident. Many forces operate against those who would upset the status quo: opposing values or theories; competing demands for available funds; the power, status, or economic reward that others derive from the pattern we propose to alter; and even ingrained human resistance to change *qua* change.

Harried officials may sometimes wish that the Committee did not exist to stir up these contests, but equally often their respect for its knowledge and dedication breeds a receptivity to its counsel and an inclination to turn to it for help. Not infrequently government officials wavering on the direction to take have sought its opinion or its support for a particular choice. On occasion, officials have asked the Committee to bring together in its conference room spokesmen for competing approaches to an issue so that they can hear a frank and free argument of the case on neutral ground. Where I have seen this happen on health matters, I believe that the Committee's convening role has made a constructive contribution to the development of public policy that is workable and address the real need.

The Committee's overriding priority in health is to insure that every child has access to comprehensive and continuous health care regardless of the economic status of his family. We never lose sight of that goal. But along the way we also have to take account of specific problems that threaten children's health. A recent case in point, and an excellent example of Committee style in action, is our work on the subject of children and AIDS.

The health section began to educate itself on this problem about three years ago and to debate how we could make a contribution. About 20 months ago we embarked on a field study to find out how well New York City service systems were coping with the present caseload and preparing for the great increase that was predicted. The Committee's familiarity with a cross section of service fields has probably never been more useful to us than in this project, which had to evaluate the multiplicity of services that these sick children and their multiproblem families require. Clearly, children with AIDS or ARC need access to skilled medical care, but they or their families usually have urgent needs for counseling, financial aid, assistance in the home, day care and schooling, often foster care, and many other services as well.

A trained task force composed of 19 members and graduates of the Committee's community leadership course plus six welcome volunteers from the United Hospital Fund visited 20 voluntary and municipal hospitals armed with a seven page questionnaire. At each institution they interviewed both medical and social service staff that dealt with these children and families. City officials and representatives of voluntary social agencies were also interviewed.

The shortfall in services that we found and our recommendations for remedying it were presented in a 61-page report published a year ago. Because we had seen so little awareness of the problem among the general public and so little inclination among officials or providers to gear up for a rising tide of new cases among children, we called our report *The Invisible Emergency: Children and AIDS in New York*. It appears to have had a significant effect in focussing attention on the children of the AIDS crisis and forcing people to come to grips with the problem. Since the publication of *The Invisible Emergency*, committees of Congress, the state legislature, and the City Council have held public hearings on pediatric AIDS. The state and city undertook new studies of HIV antibody prevalence among pregnant women and newborns, and state and city officials admitted that the outlook was more alarming than they had previously indicated.

We have been working ever since to secure action on the recommendations made in our study, using all the weapons available to advocates. The United

Hospital Fund and the Gay Men's Health Crisis have become our allies in this effort. Together we succeeded in getting the first state funding explicitly for pediatric AIDS into this year's budget in Albany, and we are hoping that the city budget as it emerges from negotiations will also include more adequate attention to the need. We shall, of course, give careful study to the strategic plan for AIDS services just issued by the city. But what is being done is late and much too little, and our advocacy for a more proportionate response cannot slacken.

I can only mention some of the other major priorities on the health section's current advocacy agenda. They include the expansion of school-based clinics to many more schools of all levels in areas where many children lack a primary care provider; our point of departure here is a field study the health section did a few years ago under the leadership of Dr. Katherine Brownell. As part of a broader Committee study of homeless children in congregate shelters, the health section is evaluating their health care. We have under way a monitoring project on access to the supplemental food program for women, infants, and children in several health districts with a high incidence of low birthweight. These efforts and the follow-up on our pediatric AIDS report consume most of our limited resources. But where we cannot mount a full scale attack on a long-term concern, we try to maintain a foothold by other means, such as assisting a coalition of organizations similarly concerned. That is the path we are following, for example, in relation to lead poisoning.

Advocacy is a long hard road littered with frustrations. But New York City children have desperate needs in every area of their lives, and effective advocacy is the only road from where we are to where we ought to be. So the Citizens' Committee for Children will be continuing its efforts and looking for allies to speed the progress.